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TITLE: Delays and Refusals in Treatment for Breast Cancer Among
Native American and Hispanic Women with Breast Cancer

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FOREWORD

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5. INTRODUCTION

Scope of the Research

Little is known about patient perceptions in the management of breast cancer among Native American and Hispanic patients. Data from the New Mexico Tumor Registry indicates that despite lower incidence of the disease in these populations, for those women diagnosed with the disease the prognosis of survival is worse, even when adjusted for stage (NMTR, 1997). Current breast cancer research focusing on these populations has been primarily epidemiological in nature. Other research suggests that acknowledgment of the cultural influences on patients' treatment decisions, including traditional health practices, is necessary to optimize the benefits of the patient-provider partnership (Maduro, 1983; Molina, 1997; Hodge, et al., 1996).

Qualitative methods have been successfully used to examine the experiences of women treated for breast cancer (Loveys & Klaich, 1991; Hilton, 1994; Pierce, 1993; Dunaway et. al, 1995). The data collection techniques in qualitative studies (in-depth interviewing, focus groups) allow for the patient to tell her story in her own words. Qualitative methods have also been recommended by researchers in the field as a method that allows women of diverse ethnic backgrounds to share their stories in a nonjudgmental way.

This study is identifying Native American, Hispanic, and Non-Hispanic White women enrolled in the New Mexico Breast and Cervical Cancer Detection and Control Program who have been diagnosed with breast cancer. An ethnographic qualitative design utilizing comprehensive in-depth interviews to describe the experiences of women who have refused or delayed treatment for breast cancer is being used.

The aims of this study are the following:

- to identify psychosocial, cultural, language, and attitudinal variables associated with the management of breast cancer among Native American, non-Hispanic white and Hispanic women;
- to identify barriers that interfere with breast cancer treatment among Native American and Hispanic women in New Mexico;
- to provide preliminary data for future studies which may assist in the development of intervention strategies to improve breast cancer treatment outcomes.

The study is enrolling a total of 70 participants, 35 patients and 35 family members or patient identified caregivers. Community members and representatives such as community health workers, breast cancer survivors, advocacy organizations such as People Living Through Cancer and the Gathering of Cancer Support, have provided input in the implementation of the study.

6. BODY

Annual Summary

Identification of New Cases

In the previous annual summary we reported the the study's enrollment goal of thirty-five Native American, Hispanic and Non-Hispanic white women diagnosed with breast cancer and thirty-five identified family members/caregivers. Participants are being identified through the breast cancer database of the Breast and Cervical Cancer (B&CC) Program. In the 1997-1998 annual summary we reported that the records of 371 patients referred for their recommended first course treatment (surgery, chemotherapy, radiation, hormonal and immunotherapy) and identified in the B&CC Program and New Mexico Tumor Registry (NMTR) database were reviewed. This review yielded a total of thirty-five participants who met the study's inclusionary criteria. This list of thirty-five potential participants was then reviewed and crosschecked to obtain patient status (living or deceased) and follow-up physician. In this reporting period 178 additional cases were identified (matched file with the NMTR, December 1998) and are currently being reviewed for study inclusionary criteria and patient status. The Programmer Analyst and the Special Studies Coordinator at the NMTR have assisted the investigator with the details of this final list.

All B&CC Program breast cancer cases (after undergoing the matching system at NMTR) who's records indicated a SEER code of "7" (patient or patient's guardian refused the specific therapy) or "8" (treatment recommended, unknown if administered) were selected as candidates for the study. In the case of surgery, cases that had a code of "10" (indicates the patient had less than a total mastectomy and or just an excisional biopsy) or a code of "00" (no surgical procedure) were also selected for review.

In the previous annual summary we reported that in order to select patients that fit the delay criteria, the investigator, manually reviewed the latest B&CC breast cancer database (matched file with the NMTR, March of 1997). This was necessary to identify patients who delayed treatment, but completed treatment later (these cases would not have codes "7", "8", or "10"). Only by examining the patient records could an assessment of delays be made.

In this reporting period, the additional 178 cases are now being reviewed on line as a result of the new changes in data collection and abstracting at the NMTR. In the late part of 1998, the NMTR's on line patient records began entering dates for treatment on each patient. This computerized method has facilitated the process of selecting patients that fit the delay criteria. Instead of manual reviews of patient records (178 new cases), a computerized list has been generated indicating dates for each treatment. Initial dates of treatment, and dates on all subsequent treatments are reflected on each patient. This list is currently being reviewed to assess any temporal delays within the first course of treatment as defined by the SEER Program Code Manual (January, 1998).

Translation of Interview Guides

The translation of the interview guide into Spanish has been completed. Two Spanish-speaking experienced translators assisted in the translation. A staff person who is proficient in both languages subsequently back translated the Spanish interview guides into English.

Review of Interview Guide

Dr. Jennie R. Joe director of the Native American Research and Training Center in Arizona, who is Navajo and a breast cancer survivor, reviewed the patient and family guides. Dr. Joe agreed for the use of a one-page "Navajo Traditional Questions" for the Navajo participants. In addition, Dr. Milagro Peña, who is an experienced qualitative researcher and published in the area of religion and spirituality among Hispanics, provided questions for use in the interview guide. The interview guides have been revised in accordance with these recommendations.

Chapter House Approval and Support Letter

The investigator presented the study to the community Chapter House in Churchrock, New Mexico at the Chapter House's planning meeting in December 1998. At that time the investigator received approval by the Chapter House. This approval from the Chapter House is required for overall Navajo Nation human subjects approval.

Early to mid 1999 there were internal changes in the governing board at the Chapter House requiring the study to be presented again at the Chapter House's planning meeting. It was once again approved and a new letter generated indicating new officers. Due to the cross-cultural nature of the research, and the sensitivity about research in their communities, this early phase of approval has taken considerably longer than expected.

Navajo Nation Health Research Review Board

As reported in the previous reports, significant developments have occurred within the Navajo Nation regarding the transition of the functions of the institutional review board to the Navajo Nation. In the last year the NNHRRB underwent further internal changes and it was subsequently re-organized. Therefore human subjects approval for research at the Navajo Nation was detained until the NNHRRB commenced its function. Submission to the NNHRRB for study approval awaited the Chapter House approval, which must accompany the application.

Unexpected Delays and Proposed Adjustments

The investigator experienced personal health crises in the last year, which had some impact on the project timeline. Remaining tasks from the Year 03 Statement of Work include completion of data collection, transcription of interviews, and analysis. Data is currently being collected and transcribers for the Navajo speaking interviews have been identified. All data is expected to be collected within the next 4 months. There was some additional delay in data collection due to the need to identify new cases, (which requires matching of the New Mexico Tumor Registry and the Breast and Cervical Cancer Detection and Control Program databases). In July 1999, a no-cost extension was submitted and approved with an end date of August 31st 2000.

7. APPENDED TO THE SUMMARY

1) Key Research Accomplishments:

- 178 new breast cancer cases were identified from the most recent (through December 1998) B&CC Program and NMTR match. Cases were reviewed for selection based on study inclusionary criteria.
- Increased support for the study from both the community of breast cancer survivors
- Increased support for the study from key members from the communities Participating in the study
- Support and approval for the study from the Chapter House in the Gallup area and health advisors working in the areas of Gallup, Crownpoint and Shiprock New Mexico.

2) Reportable Outcomes:

This will be reported in the study's final report (August/September 2000). In that final reporting the investigator will report manuscripts submitted or published findings in peer review journals, abstracts and presentation to scientific conferences, funding, research opportunities and degrees obtained as a result of this award.

3) Copies of cited manuscripts and abstracts will be attached in the final reporting of this award September 2000.